Alzheimer's Advisory Council

Executive Office of Elder Affairs
Elizabeth Chen, Secretary

December 1, 2020
3:00-5:00 pm
Video Conference

Agenda

1. **Welcome, Meeting Logistics and Introductions (15 min)**

2. **Physical Infrastructure Workgroup (10 min)**
   - Confirm wording of additional recommendation from October's Council Meeting

3. **Caregiver Support and Public Awareness Workgroup (30 min)**
   - Presentation (10 min)
   - Discussion (20 min)

4. **Research Workgroup (30 min)**
   - Presentation (10 min)
   - Discussion (20 min)

5. **Quality of Care Workgroup (30 min)**
   - Presentation (10 min)
   - Discussion (20 min)

6. **Next Steps (5 min)**

> **Incorporate age and dementia friendly (AF & DF) scoring into all state-funded physical infrastructure projects**

Implementation Strategy:

In 2021, identify and evaluate options to ensure that scoring on relevant projects includes AF & DF criteria by:

- Identifying and working with state agencies that fund physical infrastructure projects[1]

- Identifying specific projects and programs (e.g., the MassWorks Infrastructure Program) and/or statutes (e.g., Chapter 90) to include such criteria

- In 2021, incorporate AF & DF scoring criteria in at least one specific project, program, or legislative action

[1] For example, Department of Conservation and Recreation, Executive Office of Housing and Economic Development, Department of Housing and Community Development, Department of Transportation, Division of Capital Asset Management and Maintenance, Board of Library Commissioners, and Executive Office for Administration and Finance

Alzheimer's Advisory Council

Caregiver Support and Public Awareness Workgroup
12/1/20

Workgroup Leads
Barb Meehan
Hector Montesino

Caregiver Support and Public Awareness Workgroup Goals

GOAL 1 - Identify, explore, recommend **short-term strategies** to support caregivers and PLWD

1.1. Using **rapid testing**, establish opportunities for PLWD living at home and long-term care facilities to safely gather in-person and indoors with caregivers, families and friends – **Outside scope of this Council**

1.2 Establish a **volunteer-driven program** that provides respite for dementia caregivers focusing on in-person interactions PLWD – **Difficult to do in short term; can focus more on helping caregivers find existing resources**

1.3. Provide **assistive technology** to ASAPs for distribution to PLWD and caregivers – **Now available through CARES Act**

1.4 Provide **tips on how to prepare for post-diagnosis discussions** with support service providers – **Resources exist, caregivers need help finding them; can merge this with Goal 2 and care planning (Quality of Care Workgroup)**

Goal 2 - Identify approaches to **improve awareness of the pathways** to available supports and services for dementia caregivers and their care partners.

- Goal 1 recommendations were presented during October's Council Meeting

- For variety of reasons (above), we will focus today's discussion on Goal 2

- However, Goal 2 strategies can drive both goals as most can be implemented in the short term

2.1. Make and distribute three videos (English, Spanish, Portuguese) of caregivers talking about the help they got and how they got it

Implementation Strategies (Implement by May 2021)

1. **Identify interviewers and caregivers (interviewees)** for a 15-minute interview.

   - Select caregivers who care for a PLWD and benefited from available support.

2. **Prepare questions** and work with caregivers on responses.

3. **Include dementia overview** at beginning and **contact info** at the end (MassOptions & Alz. Assoc.)

4. **Disseminate video link widely,** including organizations such as:

   - MassAccess (Cable TV); senior centers (websites and newsletters); Memory Sunday churches (church bulletins); EOEA's mass.gov website; elder services network, Council member networks

2.2. Place on EOEA's mass.gov website, an overview of statewide services, supports and pathways for PLWD and their caregivers

Implementation Strategies (Implement by May 2021)

1. **Sort through existing information** and identify the most useful.

2. **Organize information into user-friendly format**; provide clear eligibility criteria.

3. **Link to town-by-town list of ASAPs and Alzheimer's Association helpline.**

4. **Post on EOEA website** under *Dementia Information and Resources*, which currently exists, but does not include this information.

5. **Distribute the link widely**, e.g., Council member networks, elder services networks, and Alzheimer's Association.

"SECRET SHOPPER" EXERCISE

Conducted to help identify potential gaps in current pathways

Goal of Exercise

Evaluate and compare the experiences of 3 caregivers of PLWD seeking help to alleviate stress due to isolation and loss of routine.

They were asked to call:

- MassOptions

- Local ASAP

- Alzheimer's Association

"SECRET SHOPPER" EXERCISE FINDINGS

1. **All three caregivers came away without help.**

2. **Lack of cross-referrals ASAPS/Alzheimer's Assoc**. - Helpful referrals do not always flow between ASAP and Alzheimer's Assoc. and vice versa.

3. **Lack of referrals to MA Family Caregiver Support Program (MFCSP)** - ASAPs not always referring caregivers to local MFCSP when it may be helpful.

4. **Automated messages can be confusing -** Some ASAPs have automated messages that may be so confusing that stressed caregivers hang up/ give up.

RECOMMENDATIONS

Detailed implementation strategies for recommendations below were provided to Council in October 2020. EOEA has agreed to implement them.

1. **Implement changes at ASAPs** to ensure that stressed caregivers get what they need in an effective and consistent manner

   - Conduct a more robust "secret shopper" exercise, identify areas for improvement at ASAPs, make improvements

2. **Make cross-referrals a standard practice** between ASAPs and Alzheimer's Assoc. (Implement by May 2021)

3. **Require that ASAP staff refer caregivers to the MA Family Caregiver Support Program** when appropriate. (Implement by May 2021)

4. **Make the ASAPs' automated phone messages clear** and easy to connect to a person for help. (EOEA is in process of implementing)

Alzheimer's Advisory Council

Research Workgroup
12/1/20

Workgroup Lead
Andrew Budson, MD

Research Workgroup

Andrew Budson, MD
Workgroup Lead and Council Member
Chief of Cognitive & Behavioral Neurology, Associate Chief
of Staff for Education, and Director of the Center for
Translational Cognitive Neuroscience at Veterans Affairs
(VA) Boston Healthcare System
Associate Director for Research at Boston University
Alzheimer's Disease Center
Lecturer in Neurology at Harvard Medical School
Medical Director of the Boston Center for Memory

Jonathan Jackson, PhD
Council Member
Founder and Executive Director
Community Access, Recruitment, & Engagement (CARE)
Research Center
Massachusetts General Hospital
Instructor in Neurology at Harvard Medical School

Renée DeCaro, PhD
Postdoctoral Research Fellow
Center for Translational Cognitive Neuroscience
Boston Veterans Affairs | Boston University
Alzheimer's Disease Center

Anna Marin
PhD Student, Behavioral Neuroscience, Boston
University School of Medicine
Center for Translational Cognitive Neuroscience,
VA Boston Healthcare System

Goal

Advance dementia research in Massachusetts

Recommendations

1. Increase diversity in *ADRD research*

2. Increase diversity of *ADRD researchers*

Challenges which led to recommendations

- Lack of representation among study populations, limiting generalizability to the wider population affected with ADRD

- Lack of diversity among researchers and study approaches to ADRD, limiting perspectives and innovation

RECOMMENDATION #1: Increase diversity in ADRD research

- Increase _racial and ethnic diversity_ of participants in ADRD research (1.1)

- Increase diversity of:

  - participants in _understudied target populations_ (1.2)

  - _the stages of ADRD_ that are being investigated (1.3)

  - _research methods_ used to study ADRD (1.4)

RECOMMENDATION #2: Increase diversity of ADRD researchers

- Increase _racial and ethnic diversity_ of ADRD researchers (2.1)

- Increase _gender diversity_ of ADRD researchers (2.2)

I.   **Increase outcomes of diversity of participants, disease stages, methods, and researchers.[1]**

In Year 1 (2021) and Year 2 (2022)

1.   Compile data for: participants, disease stages, methods, and researchers of both for-profit & non-profit organizations.

2.   Inform and educate industry companies and non-profit centers regarding new rules to come regarding required diversity of participants, disease stages, methods, and researchers.

3.   Share our recommendations with all US states plus Puerto Rico and encourage them to set up analogous programs of their own.

[1]*Advances All Recommendations and Strategic Priorities*

II. **Provide Research Support Grants[2]**

In Year 1 (2021) and Year 2 (2022)

1. Secure funding and establish application mechanism.

2. Provide sources of funding for small research support grants for increasing the diversity of underrepresented participants, disease stages, research methodologies, and researchers.

[2]Advances All Recommendations and Strategic Priorities

Responsible Organizations

TBD (e.g., NIH, donor, industry, state)

- Provides grant to non-profit organization to manage research grant program

- Provides oversight to ensure effectiveness of both implementation strategies

- Regularly reports to Research Workgroup (& therefore Council) seeking advice when needed

Non-profit organization

- Awarded grant to cover costs to manage the program, distribute research grants, conduct all outreach, compile data, and educate companies and non-profits

Costs

- $150,000 annual grant to non-profit organization for program management (beginning in Year 1)

- $200,000 for research support grants (10 two-year grants at $10K each) in Years 3-4

- Additionally, the responsible organization (TBD) would incur program oversight costs

Alzheimer's Advisory Council

Quality of Care Workgroup

12/1/20

Workgroup Leads

Maura Brennan

Linda Pellegrini

Care Planning Subcommittee Leads
Linda Pellegrini & Susan Antkowiak

Staffing & Training Subcommittee Lead
Robert Schreiber

Workgroup Members

Maura J. Brennan, MD
Council Member & Workgroup Co-lead
Program Director
Baystate Health Geriatric Workforce
Enhancement Program

Linda Pellegrini, MS, GNP-BC
Council Member & Workgroup Co-lead
Care Planning Subcommittee Co-lead
Geriatric Nurse Practitioner
UMass Memorial Medical Center

Susan Antkowiak
Council Member
Care Planning Subcommittee Co-lead
Vice President of Programs & Services
Alzheimer's Association

Mike Belleville
Council Member
Dementia Advocate

Deb Dowd-Foley
Caregiver Specialist
Elder Services of Worcester Area,
Inc.

Tara Gregorio
President
Massachusetts Senior Care
Association

Lisa Gurgone, MS
Executive Director
Mass Home Care

Laurie Herndon, MSN, GNP, BC
Project Director
Hinda and Arthur Marcus Institute
for Aging Research,
Hebrew SeniorLife

Judy Johanson
Dementia Advocate
Mass. Alzheimer's Disease
Research Center, MGH

Pam Mirick
Caregiver

Robert Schreiber, M.D.
Vice President and Medical
Director
Program of All-inclusive Care
for the Elderly (PACE)
Fallon Health

Nina M. Silverstein, PhD
Professor of Gerontology
University of Massachusetts
Boston

Goal

Identify gaps in quality of care for people living with dementia in MA and strategies to close those gaps

Recommendations

1. Care Planning - Develop a person directed care plan framework and template

2. Staffing & Training - Develop a plan that ensures that staff in primary care, long term care, home care, caregiver and patient settings across the state receive the training and support needed to build and retain interprofessional teams with expertise in dementia care

Challenges

1. Lack of / delayed diagnosis; lack of regular, comprehensive, ongoing assessments; and person-centered and person-directed care planning

2. Insufficient training, support, recruitment, and retention of skilled interprofessional teams to provide ongoing care; inconsistent and unknown quality of training; and undervalued direct care workers

RECOMMENDATION #1: Develop care plan framework and template

Beginning in 2021:

1.1 Begin development of a person directed care plan framework and template that would be directed to consumers. This tool would be put in the hands of PLWD and care partners.

1.2 Gather information, data, looking at existing tools

1.3 Meet with stakeholders and potential partners- potential partners identified include Alzheimer's Association, Honoring Choices, Dementia Friends, MA

1.4 Seek assistance of graduate student in public health, or nursing for research and writing

1.5 Seek and identify sources of funding for dissemination and marketing

Responsible Organizations

- This subcommittee along with guidance from other organizations including:

  o Executive Office of Elder Affairs, Alzheimer's Association, Honoring Choices

Costs/Resources

- No incremental costs for development as subcommittee will be responsible for developing the framework

- Costs associated with disseminating/marketing/advertising/printing

- Potential technology-related costs if the framework is incorporated into an existing website

RECOMMENDATION #2: Develop plan that ensures staff receive training and support needed to build and retain interprofessional teams with expertise in dementia care

Beginning in 2021:

2.1 Develop interprofessional training and ongoing coaching and support; use age-friendly (AF) health system and/or ECHO models

2.2 Within the AF health system, develop dementia-specific adaptations and approaches of the 4M's (What <u>M</u>atters, <u>M</u>edication, <u>M</u>entation, <u>M</u>obility)

2.3 Conduct pilot with about 6 early adopters to determine feasibility; refine approach; plan for scaling

2.4 Enhance supports and training through developing career ladders, ensuring fair wages, and inclusion in interprofessional team training

2.5 Launch PR campaign to elevate perceived value of direct care workers

2.6 Leverage expertise of existing teams and/or centers of excellence to support interprofessional training and ongoing coaching

Responsible Organizations

This subcommittee along with EOEA will coordinate and track implementation by Age-Friendly Health Systems/Institute for Healthcare Improvement (IHI), Alzheimer's Assoc., Baystate Geriatrics Workforce Enhancement Program (GWEP), and ASAPs

Costs

- Costs associated with release time needed to accommodate staff training, which will be borne by the age-friendly health system

- Costs associated with PR campaign

Resources

- MA Medical Society, Alzheimer's Assoc. Dementia Care Coordination program, UMass Boston Gerontology Institute, Centers of Excellence in MA, ECHO Albuquerque, NM, Baystate GWEP

- Existing training programs - examples have been provided to Council in today's meeting materials

Next Council Meeting

February 9, 2021; 3:00 - 5:00 pm

Presentations and Discussions on February 9, 2021:

1. Diagnosis and Services Navigation Workgroup

2. Equitable Access and Care Workgroup

3. Summary of:

   - Council's first annual report to EOHHS and Legislature

   - Alzheimer's State Plan

In the meantime, please direct any questions and materials to: Pam MacLeod – pam.macleod@mass.gov